

Testimony of Lynn Johnson on
SB 956, AN ACT CONCERNING PEDIATRIC AUTOIMMUNE
NEUROPSYCHIATRIC DISORDER ASSOCIATED WITH STREPTOCOCCAL
INFECTIONS.

Senator Crisco, Representative Megna and members of the Insurance & Real Estate Committee, my name is Lynn Johnson and I am the Executive Director of the PANDAS Resource Network (PRN), a Connecticut 501c3 non-profit. I am here to speak in support of Senate Bill 956.

“What is PANDAS?”

In 1994 Dr. Susan Swedo and colleagues at the NIMH discovered the existence of Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections. This group proposed that there was a link between Group A strep infections and the sudden onset of obsessive-compulsive disorder (OCD) and/or tic disorders in children. The suggested mechanism was felt to be an autoimmune response directed against certain targets of the brain leading to neuro-behavioral changes, similar to what happens in rheumatic fever, where the heart valve is the mistaken target of the body's natural fight against infection. Think “Rheumatic fever of the brain”.

In PANDAS the antibodies breach the blood brain barrier (BBB) and attack the basal ganglia area of the brain and set forth in motion a series of neuro-psychiatric behaviors and motor and vocal tics in its pediatric host. Recently PANDAS has been expanded to include PANS. PANS refers to the sudden onset of obsessive compulsive Disorder (OCD) but does not indicate Group A strep specifically as a cause of the syndrome. PANDAS can be viewed as a subgroup of PANS. PANS and PANDAS are comparable to cancer and leukemia (respectively) as PANS is the large class of disorders and PANDAS is one specific type.

How does this apply to me and why am I involved?

The PRN was established in early 2010 when my daughter, Lauren, became stricken with this disorder in late 2009. Lauren began sneezing 25,000x a day, overnight, and no one in our local medical community could diagnose her. A violent vocal tic that stole her life like a thief in the night. After her story attracted local, national and worldwide media attention, we found hope and healing through a handful of brilliant dedicated doctors, who helped give birth to our organization and serve on our medical advisory board. My testimony today, comes exactly one year to date, from the day I testified before this committee last year. The good news is that my daughter, Lauren continues to excel and improve with on-going treatment and she is currently a freshman honor roll student who is already looking forward to perusing a career in marine biology. If you recall, I testified last year that I had three children who suffer from PANDAS and it is with great sadness that I share with you that my son lost his battle to this disorder and tragically passed away May 4th, 2012. Our family is not alone but is joined by over 5,000 families who have reached out to our organization in the last 3 years. Families who lives have been forever altered and devastatingly stricken by this little-known disorder.

How can the State of Connecticut help?

As the bill in front of you proposes; much is needed in the form of awareness, education and research. The research to date and anecdotal evidence shows that diagnosing and treating

these children with simple antibiotics and or using a procedure called IVIG can resolve many of the symptoms if not fully resolve the disorder. To date most doctors have not heard of this disorder and many those who do are skeptical due to the lack of science based studies. By coming together and passing this legislation many lives will be saved. If such legislation was in affect in 2006, when my son first exacerbated with symptoms of PANS, he may have been here today speaking as a success story instead of a tragedy. PANDAS/PANS like many new and orphan disorders is often diagnosed simple because practitioners are unaware of it's existence and do not have the tools/education needed to help the families they serve. Insurance will often deny off-label use of life-saving effective treatment. While we are furthering this important science based research no child should be left behind. I ask you to help us help these families, to learn more about PANDAS/PANS and to support SB956.

This Friday, March 1st, Senator Crisco is graciously hosting. A large number of physicians, researchers and families will be there to share their experiences. Dr. Denis Bouboulis, our co-founder from Darien, CT who has treated over 2,000 families with PANDAS will be there to discuss the condition and answer questions. We invite you to take part in this important event and meet the physicians, researchers and families affected by the disorder.

Respectively,

Lynn M. Johnson

The PANDAS Resource Network is a Connecticut based non-profit (501c3) organization dedicated solely to fighting PANDAS syndrome through a combination of research, education, and awareness.

Mission

The Foundation's mission is to, EDUCATE, COMMUNICATE, CURE™:

Educate the medical community, patients and their families about PANDAS (EDUCATE)

Increase public and professional awareness (COMMUNICATE)

Encourage research into new treatments and a cure (CURE)

Company Overview

The purpose of PANDAS RESOURCE NETWORK is to be a leading national, non-profit advocacy group for children diagnosed with PANDAS.

Description

A non-profit 501c3 organization that is dedicated to educating patients, families and healthcare providers and supporting those who have been affected.

For its ability to advance treatment protocols and research of PANDAS based on responsible, evidence-based medical practice and to educate primary care providers and pediatric specialists about the disease, enabling children to receive an early, accurate diagnosis, effective treatment, and appropriate referrals immediately upon disease onset; to provide resources and referrals to doctors and families through the course of the disease, from the earliest onset of symptoms through to remission; and to serve as a collaborative resource for experts in the fields of neurology, immunology, psychiatry, gastroenterology,

rheumatology, psychology, and epidemiology, encouraging interdisciplinary discussion and research on PANDAS.

General Information

The PANDAS RESOURCE NETWORK™ Founded in 2010 the PRN provides families and physicians and the community with practical information and coping strategies that minimize the effects of PANDAS. In addition, the PRN is the clearinghouse for medical information and strives to be the recognized national advocate for PANDAS education and awareness.